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BREAKING THROUGH

PROFILES OF INDIVIDUALS CHALLENGING HIV-RELATED STIGMA AND
PROMOTING HUMAN RIGHTS AROUND THE WORLD

JANUARY 2006

This publication was produced for review by the United States Agency for International Development. It was prepared by the POLICY Project.





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Cover photo of Jason Wessenaar by Christina Stucky.

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The authors' views expressed in this publication do not necessarily reflect the views of the United States Agency for International Development (USAID) or the United States Government.

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ABBREVIATIONS

AIDS	acquired immune deficiency syndrome
APN+	Asia Pacific Network of People Living with HIV/AIDS
BDS	Blue Diamond Society (Nepal)
CCM	country coordinating mechanism
FWLD	Forum for Women, Law, and Development (Nepal)
GIPA	Greater Involvement of People Living with HIV/AIDS
HIV	human immunodeficiency virus
NCASC	National Center for AIDS and STD Control (Nepal)
NGO	nongovernmental organization
STD	sexually transmitted disease
USAID	United States Agency for International Development

INTRODUCTION

Around the world, in myriad ways, individuals are working to fight stigma and discrimination and promote human rights in order to combat the HIV epidemic. Asked whether she considers herself a hero, Pham Thi Hue notes: “There are so many people in the positive community who are heroes to me. Just living every day makes them heroes.”

Breaking Through highlights the contributions of people who are speaking out against stigma, discrimination, and human rights violations. Some of those profiled are people living with HIV. Hue, who helped form the HIV-positive community organization Flamboyant Flower, has used her personal story to break the silence surrounding HIV. Hout To Tem speaks of the importance of addressing stigma and discrimination in various settings. Jason Wessenaar and Anuar Luna seek to help people living with HIV overcome internal stigma. For Greg Gray, encouraging capacity building and mentoring fellow HIV-positive people is essential so that others may continue the fight.

Also profiled are allies from government, NGOs, faith-based groups, and women’s organizations—who are critical for overcoming stigma and discrimination in all its forms. Dr. Nadiya Zhylka and Purna Shrestha show how national laws and policies are effective tools for promoting the human rights of people living with HIV and vulnerable groups. At the community level, Joe Nkosi and Florence Gundo work within traditional systems and structures to address stigma, discrimination, and human rights.

It is our hope that readers will be inspired by the approaches and stories presented in this booklet. The individuals profiled represent a fraction of those who are confronting stigma and discrimination and promoting human rights. Their stories reflect the dedication and spirit of countless others who are working toward enabling environments that support the inclusion of people living with HIV and vulnerable groups and that foster effective, just responses to the epidemic.



CHUM SOMONN

HOUT TO TEM

Hout To Tem, a 44-year-old sergeant in the Cambodian police force, lowers his voice and gazes out at the surrounding village. “The problem,” he says, “is the countryside.” He’s referring to the challenges faced by HIV-positive people trying to combat stigma and discrimination in Cambodia. “If our neighbors in this village knew about my status, my wife’s hairdressing business would collapse.”

Kampong Svay is just 16 miles from Phnom Penh, but it is a world away from the capital. Located six miles from the nearest paved road, it is a typical Cambodian village nestled among rice fields, banana trees, and coconut palms. It might as well be anywhere in rural Cambodia, where 80 percent of the country’s 13 million people live.

As a police sergeant, Hout To Tem draws a salary of 93,700 riel (US\$23.42) a month. His wife’s salon—which also rents wedding dresses and tuxedos—can earn four times as much during an average month, more than enough to send the two children to school.

With a few head of cattle, a small mango plantation, and a solid timber house, they are doing well for a rural family in East Asia’s poorest country. But all of this hinges on the success of his wife’s business—and the neighbors not finding out about his HIV status. The prospects of that happening seem unlikely,

however. Like most Cambodian civil servants, Hout To Tem has a second job as the main source of income. In fact, he only spends weekends in Kampong Svay. During the week, he stays with his mother in Phnom Penh. And from an office in a red-light district behind the French embassy, he leads a very public life as founder and president of Vithey Chivit, a support group for people living with HIV set up in 1998.

Vithey Chivit initially had 27 members, a diverse group of housewives, soldiers, widows, widowers, and many single people. Operating on an initial budget of 20 dollars a month, it was founded with the aim of helping people living with HIV get services, including hot-line counseling and referrals as well as home and hospital visits.

“We used to face a lot of discrimination,” Hout To Tem says, referring to a former office in a nearby part of town. “We couldn’t eat at the local restaurants. People would say things when we walked down the street. Some people even complained. But in 2000 or 2001, things changed. Some of the local people came to see for themselves. They attended our meetings and some are now even members.”

Vithey Chivit—which roughly translates as “road of life” in English—cites discrimination as one of the three main challenges for HIV-

positive people in Cambodia. The others are poor housing and lack of access to antiretroviral drugs. Cambodia's HIV prevalence level is the highest in Asia, yet only 3 percent of those infected are estimated to be getting treatment.

While discrimination against people living with HIV has declined markedly in Phnom Penh in recent years, it still persists, notably in the public health sector where patients are often forced to pay for treatment that is supposed to be free. Under a pilot project funded by the POLICY Project, Vithey Chivit set up a network of informants in three major public hospitals in Phnom Penh. The network includes six people—a person living with HIV and a medical staff member in each hospital. The six-month project identified 17 cases of human rights violations that were subsequently referred to local human rights groups. Vithey Chivit found the level of stigma and discrimination to be “relatively high” in each of the three hospitals.

The other component of the pilot project involved carrying out six advocacy¹ skills

building workshops with 162 medical staff and 72 people living with HIV. The results of tests conducted before each workshop were revealing. Only 70 percent of healthcare workers and 30 percent of people living with HIV were aware of the Cambodian law on HIV passed in 2002. At the same time, their knowledge of provisions contained in the law, which prohibits discrimination by health institutions, was limited.

Under a 10-month extension of the project that started in 2005, Vithey Chivit is expanding the skills building workshops to another two public hospitals in Phnom Penh and three provincial hospitals close to the capital. Two workshops are being conducted in each

hospital. And a similar network of informants is being set up in the five hospitals, with Vithey Chivit helping to arrange meetings every two weeks to discuss problems with hospital directors.

Hout To Tem says the collaboration with POLICY on the human rights monitoring project is the largest endeavor Vithey Chivit has

“We used to face a lot of discrimination ... But in 2000 or 2001, things changed. Some of the local people came to see for themselves. They attended our meetings and some are now even members.”

■ Hout To Tem

¹ When used in this booklet, the term “advocacy” refers to targeted actions directed toward decisionmakers with the goal of promoting policy dialogue and change around specific issues. Advocacy moves beyond simply raising awareness to promoting concrete strategies and actions for addressing priority issues. Advocacy is a tool that civil society groups can use to encourage leadership, commitment, and broad-based support for HIV-related policies and programs.



CHUM SOMONN

undertaken since the organization was founded seven years ago. Under the project, 11 staff members have also received training in policy advocacy and presentation skills.

Today, Vithey Chivit has 132 members ranging from 20 to 55 years in age. The group works closely with 119 orphans and children affected by HIV in the neighborhood. The children come from 84 local families and many live with their grandparents. Some family members have joined Vithey Chivit as well.

Once the current project is complete, Hout To Tem is keen to extend Vithey Chivit's activities

to provincial hospitals in the coastal municipality of Sihanoukville and remote rural areas, such as Siem Reap, one of the poorest provinces in Cambodia, and Battambang near the border with Thailand. Unlike many health ministry officials who are reluctant to leave jobs in urban areas, Hout To Tem feels comfortable in the countryside. "I'd like to do more work in the provinces," he says.

Written by Peter Starr, a freelance writer based in Phnom Penh, Cambodia.



BARAKA KARAMA

FLORENCE GUNDO

and the Women of Orongo

“Had I not joined the Orongo Widows and Orphans Group, I would be dead by now.”

Betty Atieno is a 28-year-old mother of three children. Her husband died in 2001. Shortly after her husband’s death, her parents-in-law told her she had to be inherited by their other son. Betty refused to be inherited because, although her brother-in-law did not have a wife, she did not love him.

Her brother-in-law, however, would not take no for an answer. He would come home drunk and physically abuse her. Each time he did that, Betty would move out of her matrimonial home and stay with friends. Then one day he gave Betty an ultimatum: she would either become his wife or be thrown out of her home. Betty, who had already lost her parents to AIDS, lost hope.

“At that point I considered hanging myself and my children. I thought if I left them behind there would be no one to care for them,” Betty recalls. Then a friend told her about the Orongo Widows and Orphans Group. It has been three years since she joined the group and Betty says she now knows better.

“I now know I have rights and I will not run away the next time my brother-in-law assaults me. I will simply report him to the local chief. I know the Orongo group will back me.”

Betty is just one of 56 widows who are members of the Orongo Widows and Orphans Group. The group was founded by Florence Gundo in 1999. Its offices are located 5.5 miles from Kisumu town in Western Kenya in an area with one of the highest HIV prevalence rates in the country.

Florence says wife inheritance is a widespread practice in her community and it makes the women more vulnerable to HIV.

“A lot of our customs expose us to the danger of acquiring HIV. When you are inherited by your brother-in law, it’s almost impossible to ask him to get tested for HIV. Yet, most widows will still accept to be inherited for fear of a curse,” Florence explains.

Wife inheritance and the dangers inherent in it was one of the issues that compelled Florence to form the Orongo Widows and Orphans Group. The practice is deeply rooted in the Luo community, which Florence belongs to, because—as in many African communities—they believe a wife is the property of the community.

“I noticed that most widows were resorting to brewing and selling illicit liquor, and orphans were being used as herdsboys and maids. I knew I had to do something,” Florence remembers.

After Florence attended a women's property rights awareness workshop organized by the POLICY Project, she went back home and mobilized widows in her community so she could teach them about their rights. Florence has been part of a core group that has worked with POLICY from the inception in designing and implementing an ongoing project on women's inheritance rights.

"We started teaching women in churches, schools, and even during funerals, and gradually their attitude started changing. If a woman knows her rights, she will not follow a custom that will not do her any good," Florence says.

The Orongo Widows and Orphans Group did not start out as a women's rights advocacy organization, but it has done more to secure the human rights of widows, orphans, and others in the community than even some legal aid departments or companies.

For example, it has succeeded in reclaiming land that was snatched from widows and orphans. In addition, four women who are members of the group have refused to be inherited and have also been able to assert their rights to own property in their matrimonial homes.

Apart from learning about their rights, Florence says the inheritance rights project has encouraged members of the group to learn their HIV status and this, in turn, has led them to accept those living with HIV among them.

As Florence explains, "Before, most people would not share a meal or even shake hands with someone living with HIV, but now we

know how HIV is contracted and that is changing."

The group still faces some challenges. It cares for more than 300 orphans. Providing adequate food and support for them is a monumental task. And, while the Kenyan government started providing free primary education in 2003, the group depends on donations from well-wishers and bursaries from the government to be able to send the orphans to high school.

The Orongo Widows and Orphans Group is also teaching its members to be self-reliant by ensuring they acquire skills in tailoring, horticulture, and soap making. The women are then able to buy food with the proceeds. Some members of the group have also been trained by health facilitators and provide home-based care to those living with HIV.

Most members, like Rispah Seme, are happy that they are now economically empowered. Rispah is 67 years old. She takes care of six grandchildren. Before she joined the Orongo group, she brewed and sold illicit liquor.

"I was spending so much money and I couldn't make a profit because I had to pay a protection fee. I drank a lot due to frustration. When I joined the group, I accepted Jesus as my personal savior. I now weave mats and I earn an honest income," Rispah explains. She says the money is not enough, but she believes "a persistent worker is the one who reaps." God, she says, will take care of tomorrow.

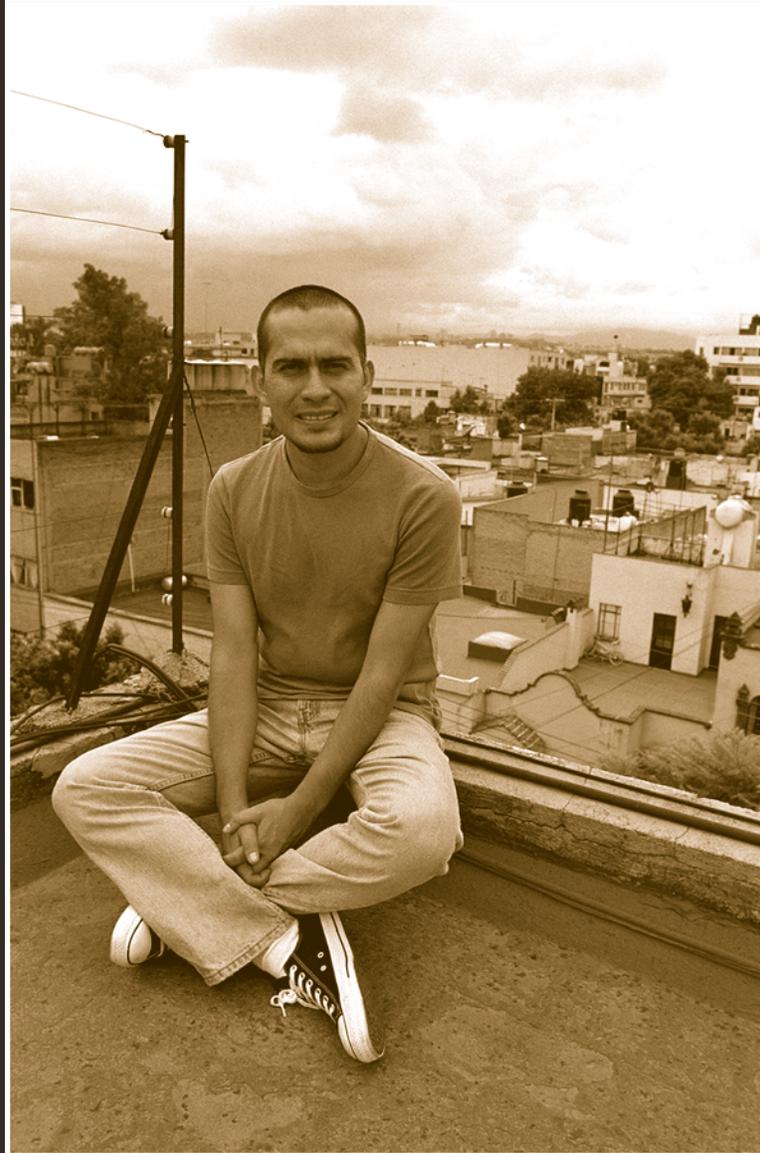
Written by Anne Waithera, a journalist for Citizen Radio based in Nairobi, Kenya.

“We started teaching women in churches, schools, and even during funerals, and gradually their attitude started changing. If a woman knows her rights, she will not follow a custom that will not do her any good.”

■ Florence Gundo



BARAKA KARAWIA



RICARDO RAMÍREZ ARRIOLA

ANUAR LUNA

Anuar Luna is one of the most visible faces of HIV in Mexico. For the last 13 years, since he was fired from his job due to his HIV-positive status, Anuar has devoted himself full time to support fellow people living with HIV.

“We have to focus on the person,” he states, “because the first impact of the epidemic is at a personal level.” For this reason, Anuar’s current goal is to help others identify and address fears, guilt, shame, and all those negative feelings related to the internal stigma of living with HIV.

“If people feel bad about themselves, they will not turn to health services. If they feel guilty, they will not ask for support from a human rights office because they will think that they do not have any right,” Anuar explains.

The 37-year-old activist knows exactly what he is talking about. “I have suffered discrimination myself,” Anuar states, recalling the moment he was fired after he was found to be HIV positive. This occurred around the time when he was to be promoted as a trusted employee in *Petroleos Mexicanos*. Anuar sued the company and lost the lawsuit, but not the courage to continue fighting.

He has told his story countless times so he can help to raise awareness. Before getting involved in the fight against HIV, Anuar, then 21, longed to become a writer. In the mornings, he worked

as an assistant and in the afternoons he attended a school for writers, but discrimination changed his life.

Anuar lives in the same building that houses the headquarters of his association, the Mexican Network of People Living with HIV/ AIDS (*Red Mexicana de Personas que Viven con VIH/SIDA*). The organization was founded by Anuar and his peers in 1997 at the time of the fight for access to antiretroviral treatment in Mexico. Unlike many other organizations that emerged that same year, the Network—as it is informally called—has focused on strengthening individuals’ capacity to cope with adverse situations and stigma that may arise as a consequence of living with HIV.

“We realized we had to empower people,” explains Anuar at the end of his workday. It is Tuesday afternoon, a day on which HIV-positive women and men come to the Network for advocacy and skills building training. Every week they deal with a different subject.

The highly-populated City of Mexico is the city with the highest number of people living with HIV. Most of the cases are found among men who have sex with men. After the leftists took office in this city in 2000, a specialized hospital to treat AIDS patients who lack social security was created. The *Clinica Especializada Condesa* is located in the same district as the Network’s

head office. Thus, its members decided to operate a bank for HIV-related medications that serves between 10 and 15 low-income people daily—who are in need not only of medical consultation, but of emotional support as well. Tuesday workshops serve that purpose.

“That health center is our contact with the grassroots, that is where we recruit people [to participate in the workshops],” explains Anuar.

The Network is a small organization with only 10 members, men and women between 25 and 37 years old, who are well trained to coach people, to support them during the empowering process, and to develop participatory methodologies to improve their quality of life. These efforts have resulted in the handbook *Soltando el lastre del anonimato* (“Dropping the Burden of Anonymity”), which aims to support people living with HIV in their process of facing their situation or speaking in public.

“That handbook was our first approach to the subject of stigma; we wrote it from a sincere need,” recalls Anuar.

Currently, the Network is focused on reducing the impact of the stigma that affects HIV-positive people. In 2003, as a pilot project funded by the POLICY Project, the Network

“If people feel bad about themselves, they will not turn to health services. If they feel guilty, they will not ask for support ...”

■ Anuar Luna

carried out a diagnosis of internal stigma based on interviews and focus groups involving 45 people living with HIV from three states across the country. According to Anuar, one of the most striking findings of the study was the participants’ tendency to avoid any kind of emotional life.

“We discovered a series of repressed feelings and frustrated desires that were generating a loss in their quality of life,” Anuar says, getting more animated as he describes this part of the project.

“We have to help them to get back those emotions and desires so as to recover the lost quality of life,” he suggests enthusiastically.

In Mexico, unlike other countries, the problem is no longer one of access to medication—almost all the people living with HIV are under antiretroviral treatment. The problem is a lack of adherence to such treatments and, according to the activist and counselor’s prediction, this problem will not be solved as long as people fail to overcome the obstacle of internal stigma.

Anuar believes that what people need to confront this type of stigma is “to develop tools that will help them manage their lives.” This year, the Network hopes to publish a couple of handbooks about the meaning of internal stigma and how to face it. For each of the

challenges identified in the diagnosis, appropriate methodologies are being developed that can be applied within the multiple self-support groups that meet in the hospitals that provide treatment and care for HIV-positive people.

The stigma project and research has triggered other projects and activities within the Network, such as the training of counselors with the goal of incorporating approaches to reduce stigma and discrimination in their workplaces. In addition, Anuar is collaborating with POLICY on the task of developing indicators to measure HIV-related stigma and discrimination and assess impact of stigma mitigation strategies to be used in Mexico and other countries.

With an ironic smile, Anuar answers a question about the difficulties that people like him who have disclosed their HIV-positive status must face. “I’ve been hit several times,” he replies somewhat amused and sad when he recalls his difficulty to have a stable partner. He has no problem with being gay, but the fact that HIV is a barrier to building a life with another person is a real burden.

For the time being, Anuar’s workmates and friends are his motivation in life. For one reason or another, he is the group leader and that, he states, has conferred on him a series of responsibilities and obligations that, in the past months, he has started to pass on to his mostly trained peers. This has enabled Anuar to have some free time and re-focus on his initial desire to become a writer.

Written by Alejandro Brito, director of Letra S.



“We have to start with the person, because the first impact of the epidemic is at the personal level.”

■ Anuar Luna

PHOTO COURTESY OF PURNA SHRESTHA



“As part of the human rights movement, FWLD sees the law as a tool for social change, and we started to brainstorm about how to address these issues from a legal point of view.”

■ Purna Shrestha

PURNA SHRESTHA

Purna Shrestha is a lawyer with the Forum for Women, Law, and Development (FWLD) in Kathmandu, Nepal. FWLD is an NGO whose mission is to eliminate all forms of discrimination against women in Nepal and to protect and promote human rights through research, public education, advocacy, legal aid, and litigation.

Purna received her master's degree in Women's Studies and started working at FWLD in July 2000. She gradually realized that the law is everywhere and that it needs to be understood as a tool that can be used to make change, and therefore decided to pursue a law degree. When she graduated with an LLB from Nepal's Tribhuvan University in 2003, having obtained her license to practice law, Purna dedicated her work to using the law as a means to promote human rights.

"As part of the human rights movement, FWLD sees the law as a tool for social change, and we started to brainstorm about how to address these issues from a legal point of view. We have started many campaigns to raise awareness of fundamental human rights, but we also wanted to look at how the law can address human rights, which are the fundamental rights guaranteed by the Constitution of the Kingdom of Nepal," Purna explains.

Through FWLD, Purna began working in the area of HIV when the issue was just starting to emerge in Nepal. Addressing HIV in Nepal is a challenge due to marginalization of vulnerable groups, and lack of awareness and support from the general public and policymakers who have a role in protecting human rights. The epidemic is still considered to be a health issue in Nepal and, therefore, it is not considered a legal issue. In contrast, Purna explains, FWLD recognized that HIV was not just a health issue, but a human rights issue because of the many rights violations committed against people living with HIV due to fear and ignorance.

Stigma and discrimination affect not only those who are HIV positive, but also groups who are believed to be associated with the virus. Nepal is facing a concentrated epidemic that primarily affects vulnerable groups. These most at-risk groups continue to face harassment and exploitation. Political instability and human rights violations by the State itself (e.g., security forces and law enforcement authorities) against injection drug users, men who have sex with men, and sex workers further exacerbate the vulnerability of already marginalized groups. For these reasons, Purna recalls, FWLD recognized that there was a natural link between its ongoing human rights work and the need to address HIV.

HUMAN RIGHTS PROTECTION ESSENTIAL FOR HIV PREVENTION: AN EXAMPLE FROM NEPAL

Outreach to vulnerable groups is needed if Nepal is to control the spread of HIV. However, in July 2004, a case was filed by a private lawyer in the Supreme Court against the Nepalese government (Ministry of Home Affairs, Ministry of Law, Justice and Parliamentary Affairs, and Secretariat of Council of Ministries), accusing it of silence and no action against an NGO that the suit claims promotes open homosexual activities.

The NGO in question is the Blue Diamond Society (BDS), the only organization that provides sexual

health and HIV services for local networks of sexual minorities in Nepal. This case has created discussion about the existence of homosexuality in Nepal, as well as the legal status of men who have sex with men.

FWLD and BDS have been working with various government agencies and NGOs to ensure the rights of men who have sex with men. Support from FWLD, including findings from the legislative audit, has been instrumental in enabling BDS to explain the legal situation of men who have sex with men

in Nepal. FWLD is assisting BDS to defend its case, and both organizations have been collecting international best practices from organizations and lawyers around the world to draft their intercession. FWLD is the only organization that has been outspoken in support for BDS, and has offered the organization tremendous support.

“The case has and will continue to be emotionally very difficult, and FWLD has been very supportive,” states Sunil Pant, Executive Director of BDS.

The POLICY Project and FWLD had been working together to enhance the capacity of human rights groups to respond to the challenges of HIV. However, both groups realized that in order to make a difference, they needed to conduct a review of how the Nepalese legal system responded to HIV prevention from a human rights perspective.

The resulting collaboration, Purna states, “...helped us to realize the importance of, and helped us work towards, creating a conducive policy environment by working with various stakeholders—such as government, law implementers, police, and vulnerable groups—in order to push for legislation.”

In 2003, with technical assistance from POLICY, FWLD conducted a legislative audit of Nepal’s compliance with the International Guidelines on HIV/AIDS and Human Rights. Although FWLD had past experience with mapping laws and working for legal reform, the legislative audit was a completely new methodology for the organization.

“The legislative audit allowed us to look at where [Nepal] stands in comparison to the International Guidelines on HIV/AIDS and Human Rights. It enabled us to determine where we should be, and identify the gaps that need to be addressed,” Purna explains.

The legislative audit also enabled HIV to be viewed from a different angle. “We’ve seen many organizations emerging that have started to raise awareness about HIV and human rights,” Purna says.

As a result of the legislative audit, FWLD and POLICY have taken the lead in drafting an HIV/AIDS ordinance that takes into consideration the gaps identified in the audit. Various stakeholders have been involved in the process of preparing the draft ordinance, including vulnerable groups, people living with HIV, government bodies, Nepal Police, medical professionals, lawyers, and others. A multisectoral, participatory planning process can help empower those who participate in the process; educate various stakeholders of the needs and assets of other affected groups; and promote ownership and buy-in across sectors.

“This process has helped to raise awareness of the importance of an enabling policy environment in the fight against HIV and of the value of considering HIV in terms of human rights,” Purna states.

FWLD and Purna continue to provide legal aid to at-risk groups who are exploited or victimized by the State due to their status or behavior. “We are trying to protect their human rights,” Purna explains.

While Purna will soon leave FWLD to pursue her studies, she intends to remain active in the field of HIV and to contribute to her country.

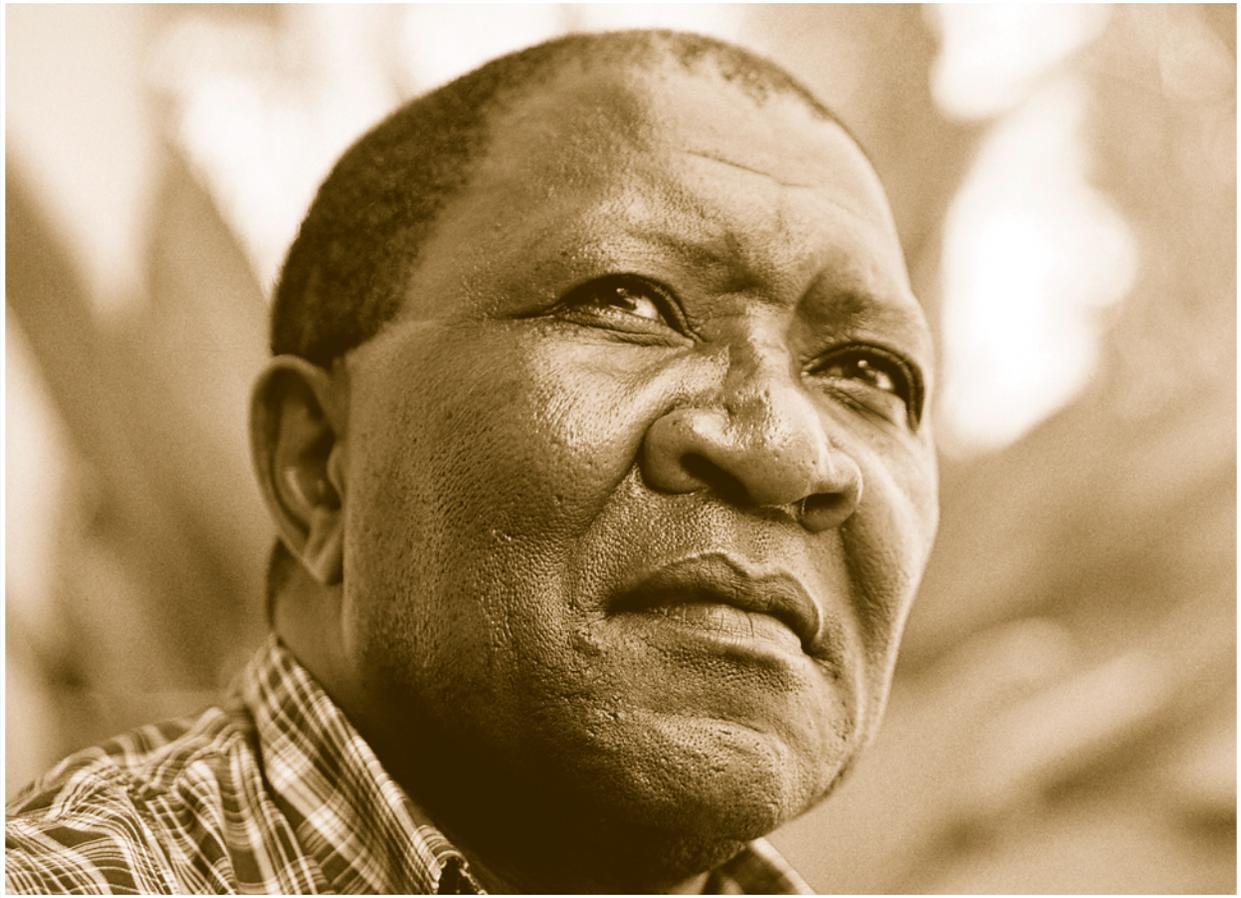
“HIV is a social issue; it is about social and personal life. This master’s program will enable me to further my work in Nepal, and make a

“The Legislative Audit allowed us to look at where [Nepal] stands in comparison to the International Guidelines on HIV/AIDS and Human Rights ... This process has helped to raise awareness of the importance of an enabling policy environment in the fight against HIV, and of the value of considering HIV in terms of human rights.”

■ Purna Shrestha

difference,” pledges Purna, who has received a scholarship from the University of Toronto to complete an LLM in Sexual and Reproductive Health Law.

Written by Nadia Carvalho, POLICY Project Mekong Regional Manager.



CHRISTINA STUCKY

JOE NKOSI

As a 61-year-old pensioner and Catholic, Joe Nkosi may not fit the standard image of a volunteer in the fight against HIV, but what he may lack in youthful zeal he makes up for in passionate commitment to people.

It seems no coincidence that Joe was born in a place called Hopetown in South Africa's vast and arid Northern Cape. Hope despite searing poverty and unemployment, hope despite HIV and AIDS—this is what informs his work in the St. Joseph's Catholic parish in Eersterus, a formerly "colored" (mixed race) township near Pretoria.

Joe has done missionary work as a layperson in the Catholic Church since the early 1960s, and though his career included years in the printing industry as well as in a large South African bank and in the Department of Agriculture, his "passion for community work"—as he puts it—remained a constant.

His involvement with the people of Eersterus began in 1970. Through the church, he worked with Lifeline, Alcoholics Anonymous, and Child Welfare. He also raised funds for World Vision around poverty-related issues. Then AIDS touched his life. First, two of his nieces contracted HIV, then a third.

"This really struck me. They were in their 30s, married, with children. Now it [AIDS] was

coming closer to the family. It was of great concern," Joe recalls.

Soon after this reality hit the family, the Southern African Catholic Bishops Conference called on all members of the church, including laypeople, to become involved in the fight against HIV.

"We were asked to stand up and be counted as infected and affected [by HIV]. I was affected. That was a turning point in my life," he explains.

The St. Joseph parish responded to the call and founded the St. Joseph's HIV/AIDS Support Group in 2002. Joe has been its chairperson since inception. After exploring the many needs of people affected by HIV, the group focused on caring for children orphaned by AIDS.

In 2004, Siyam'kela (a Nguni word meaning "We are accepting") approached St. Joseph's parish and asked its members to become trainers. Siyam'kela is a joint project of the University of Pretoria's Centre for the Study of AIDS, the South African Department of Health, USAID, and the POLICY Project that seeks to reduce HIV-related stigma and discrimination. At the end of 2004, 16 members of the parish—including nurses, doctors, social workers, and Joe—completed the training program. Among the skills the 16 parishoners were taught were ways to destigmatize HIV.

As homework, trainees looked at the scripture to see how biblical texts could be used to destigmatize rather than stigmatize people living with HIV and then organized a candle lighting memorial service to raise awareness of the impact of HIV on the community.

Since completing the training, Joe explains, “We approach our community with more confidence and more insight into HIV. Any project we tackle is with vigor and it’s well planned. There’s total commitment.”

But stigma and ignorance are not overcome only with candle lighting ceremonies. Joe himself wonders, “How many more memorial services will we have to hold?”

He believes the greatest challenge is lack of education. “There are many educated people in the parish, including graduates, but there is ignorance and there are many people who are ill-informed around HIV,” he says. “As a faith-based organization, it is up to us to make a breakthrough. Religion plays a big role. People are not willing to come forward to assist in destigmatizing HIV. Their perception is that immorality and sexual promiscuity cause HIV and people look down on people living with HIV.”

The other great challenge is poverty. Poverty makes it harder to encourage people to go for voluntary testing and counseling, he says.

“What do you promise them? How can you tell them to take pills on an empty stomach?” Joe asks. But both the affluent and the very poor reside in Eersterus. As Joe explains, some of the affluent “look down on the poor who they see

as the carriers [of HIV],” yet they will engage in commercial sex with them. “They are poor, decent people who have no other option. One guy with a flashy car can have four, five girls. Most resistance [to HIV education and acceptance of people living with HIV] comes from the affluent side of the community. But it’s the poor who carry the brunt of discrimination and the disease.”

As a practicing Catholic, Joe is often confronted with the dilemma of church doctrine versus the realities faced by communities like Eersterus. Parents in St. Joseph parish, in particular, often grapple with the Catholic Church’s stance against premarital sex and condoms when they know their teenagers are tempted by or pressured into having sex.

“It centers around morals. Much as we love to compromise rigidity, to a certain extent we have to try to sell Catholic doctrine to Catholics themselves. For us as Catholics it’s confusing. I, too, have to go to the dark areas,” he says.

Joe recommends greater cooperation among churches and religions. “A closer cooperation between various ministries would be a good vehicle for breaking stigma. We must make use of resources within the church and explore all the possibilities to combat HIV. We have to satisfy material and spiritual needs, but you can’t take care of the spiritual needs without caring for the basic needs.”

He has become aware that he must protect his own needs as well. There is nothing tranquil about his chosen form of retirement—given his chairmanship of the support group, his participation in a national HIV reference group

“As a faith-based organization, it is up to us to make a breakthrough. Religion plays a big role.”

■ Joe Nkosi

for faith-based organizations, and his seat on the board of directors of an NGO in Eersterus that offers voluntary counseling and testing and home-based care, not to mention his ongoing business interests.

“The difficulty is when I start, it’s a matter of HIV and nothing else,” Joe says. He is aware of the dangers of becoming consumed by his vigilant engagement in fighting the spread of HIV and the stigmatization of people living with HIV. His stationery and cleaning supply businesses have been somewhat neglected because of his involvement in HIV work. “But I’m not saying this because I want pity. The point is,” he says emphatically, “I am totally committed to the fight against HIV and stigmatization in our country.”

Written by Christina Stucky, a freelance writer and media trainer based in Johannesburg, South Africa.





CHRISTINA STUCKY

JASON WESSENAAR

The desire to contribute in some way, however small, to the fight against the spread of HIV is shared by many—but few act on it. Jason Wessenaar did.

Driven by the need to “do something,” anger at the deaths he was seeing around him in South Africa’s most famous township of Soweto, and the fear that he could contract the virus himself, Jason became involved in HIV work in 1994—a time of transition in South Africa, following its first non-racial elections. While he says that this momentous period in South Africa’s history did not influence his decision to leave his job as an accounts clerk to join HOPE Worldwide, his experiences under apartheid did.

“I’ve been marginalized as a black person,” he says, linking this sense of marginalization as a black man growing up in apartheid South Africa to his work with those South Africans who are now marginalized most: people living with or affected by HIV.

His journey to working in the areas of stigma and discrimination was not linear. In between two stints at HOPE Worldwide, Jason worked in the corporate world and at the National Bargaining Council for the road freight industry. There, he spent two years counseling and educating truck drivers and sex workers on HIV—two groups of people who live on the margins of society.

In 1999, Jason was diagnosed as HIV positive, turning the epidemic into a lived experience. His family, though supportive, grappled with his diagnosis in different ways.

“My mother still can’t handle it, because of her belief that I will be cured,” Jason says. “Initially there was shock and depression.”

The impact of his disclosure was significant on his two younger brothers. One of them joined an HIV vaccine study, partly because of his need to do something. One of them abstains and has often spoken with Jason about safer sex. As Jason explains, “He sees it’s not just on TV—it’s here, it’s real.”

The personal impact of his diagnosis and the HIV work he had done until then was very specific.

“It moved me from providing information and counseling to ‘What do I do in terms of stigma and discrimination?’, ‘What do I do to help people who are marginalized?’.”

In some of his closest relationships, Jason has felt the sting of stigma when partners were afraid to touch him and close friends either disappeared or became over-caring and over-supportive.

“I think [stigma and discrimination] work is difficult, but it’s a challenge I look forward to because it’s groundbreaking. Because now you are dealing with the real issues of why the epidemic is growing.”

■ Jason Wessenaar

Jason joined Siyam’kela (a Nguni word meaning “We are accepting”) in 2004. The joint project of the University of Pretoria’s Centre for the Study of AIDS, the South African Department of Health, USAID, and the POLICY Project, aims to reduce HIV-related stigma and discrimination. Through Siyam’kela and the Centre for the Study of AIDS, Jason has focused his HIV work on stigma and discrimination, specifically internal stigma.

In the community where Siyam’kela has worked, the formerly “colored” (mixed race) community of Eersterus near Pretoria, HIV is still seen as a “black disease.” The prevailing attitude is “it’s not affecting us,” Jason says. The fear to disclose one’s status is strong in Eersterus, as are community attitudes surrounding morality and judgment.

“I think it’s mainly fear, not ignorance as such. People have been brought up that you shouldn’t

have sex before marriage. If you are infected with HIV it means you’re promiscuous or gay,” he says. “Gayness as such is not an issue, but if it’s mixed with HIV, then it’s an issue of morality.”

Overtuning these learned behaviors and ingrained beliefs is the basis of Jason’s educational purpose—the hope that stereotypes can be revised and past wounds be healed is part of what drives him.

“Specifically, when working with people living with HIV, it’s very fulfilling. It’s people developing themselves and growing and overcoming their own issues even before they are diagnosed,” he explains. “I think [stigma and discrimination] work is difficult, but it’s a challenge I look forward to because it’s groundbreaking. Because now you are dealing with the real issues of why the epidemic is growing. [It’s about] understanding how our upbringing, our culture, our moral issues, and our own fears are impacting on the epidemic and what we can do about it.”

The 31-year-old also uses the media as a platform to combat stereotypes and stigma by engaging with the media on the issue of language and by hosting a television program called “Siyayinqoba” (“Beat it”).

“I don’t introduce myself as ‘Hi, I’m Jason. I’m HIV positive.’ I’m not defined by that. When I talk, I talk from my own experience and it’s not scripted or censored.”

Jason understands firsthand the importance of the greater involvement of people living with HIV in overcoming internal stigma. Working on the development of a toolkit for HIV-positive

people and more recently as a member of a national reference group for the Siyam'kela stigma project has been very empowering, Jason notes. Through this involvement, he has “grown from someone who was partially disclosed and without guidance” to someone who now is fully disclosed.

Much work lies ahead to assist South Africans affected by HIV to come to terms with the virus and the epidemic and its effect on their communities.

“I don't think stigma is understood well enough. To an extent people understand their rights, but not around sexual issues and the

right to receive healthcare. The [government's] rollout of antiretrovirals raises issues around confidentiality and poverty and unravels other issues. I'm not sure how ready people are to deal with these issues and [their] impact,” Jason says.

However, Jason believes that “once people see the impact of HIV, it will affect stigma. Once people understand [the epidemic's] importance, we won't be the only ones talking—everyone will be making noise.”

Written by Christina Stucky, a freelance writer and media trainer based in Johannesburg, South Africa.





NADIA CARVALHO

GREG GRAY

In 1999, at the recommendation of a nurse at a clinic in Hong Kong, Greg Gray attended the 9th International Conference for People Living with HIV/AIDS in Warsaw. Seeing the number and diversity of people living with HIV at the conference, Greg thought to himself: “Why are we not more vocal?” At that point, he realized the need for a stronger HIV-positive community movement and voice.

“I knew there was a need to do something,” recalls Greg, who now lives in Bangkok, Thailand, and serves as the Regional Coordinator of the Asia Pacific Network of People Living with HIV/AIDS (APN+).

Following the conference—with mentoring from Brenton Wong, Loretta Wong, and Paul Toh, among others—Greg helped set up a peer support group in Hong Kong that was linked to the APN+ Secretariat based in Singapore. Greg remembers how much there was to learn in terms of HIV-positive community development in the NGO sector, and how the fundamental issues of stigma and discrimination, human rights, and acceptance influenced the entire process.

There are many aspects of stigma and discrimination in Asia, resulting from society’s attitudes and behavior toward people living with HIV and marginalized groups, in general. According to Greg, the biggest challenge to date

is that too few people are involved in the movement in the region, and there is a need to encourage stronger leadership among people living with HIV themselves to be involved in the efforts to reduce stigma and discrimination and promote human rights.

“The mission of APN+ is to mentor and build the capacity of people living with HIV, to get more positive people involved in leadership,” Greg explains. “This is the only way to truly see the greater involvement of people living with HIV [GIPA] as a meaningful principle, and a certain means of putting the GIPA Principle into practice.”

While the GIPA Principle was first articulated in 1994, 12 years later, it has not been fully institutionalized. Greg believes very strongly in the need for greater HIV-positive community involvement.

“By empowering and educating people living with HIV, they can see the bigger picture and realize the importance of a rights-based approach to addressing stigma and discrimination. We are building a whole movement, it’s not just about people living with HIV, it’s about human rights, and everyone can learn from this issue,” Greg says.

When the APN+ Secretariat was relocated to Bangkok in 2003, at first, it was just Greg as

Regional Coordinator in the office. With support from the POLICY Project, Greg prepared a proposal to strengthen APN+'s role in the region. By building the organizational capacity of APN+, the network was able to establish and raise its regional profile and credibility. The APN+ Steering Committee has now established a clear vision and statement of purpose.

As a result of organizational strengthening, Greg explains, "We know the importance of documentation and institutional memory, and can now explain ourselves better to potential donors. Our profile as a network has been significantly raised; we are now approached by donors and there is more information sharing and communication."

APN+ focuses on several priorities, including:

- Providing a strong, proactive voice to advocate on behalf of people living with HIV in the region;
- Promoting equal and meaningful representation of HIV-positive people on relevant decisionmaking bodies; and
- Fostering opportunities for people living with HIV to develop a range of skills and build their capacity to effectively respond to the challenges of living with HIV.

Among the network's focus areas are the reduction of stigma and discrimination and promotion the human rights of people living with HIV. For example, APN+ created a stigma and discrimination tool during workshops in

the Philippines and Cambodia and became the first HIV-positive community network in Asia to undertake a comprehensive assessment of GIPA, stigma, and discrimination in the Mekong Region (Cambodia, China, Lao People's Democratic Republic, Thailand, and Vietnam) for USAID.

APN+ currently has three staff members, with plans to hire at least two more within the near future. Staffing has been a challenge as it is difficult to find people who can openly identify themselves as HIV positive.

Another challenge for APN+, according to Greg, lies in the need to listen more carefully to what the HIV-positive community needs APN+ to do on their behalf. As part of this endeavor, Greg believes APN+ should focus on strategic planning for the needs of people living with HIV five years from now, including longer term care, availability of antiretrovirals, and access to treatment.

Greg believes that the network needs to further promote the role of HIV-positive people. "We need to act professionally, with accountability and transparency, to show that we can and we do have a role to play in the response. We must also strengthen our role in prevention, including public speaking, because without people living with HIV taking a role in prevention, there will not be much headway made in controlling the epidemic," he explains.

As Greg points out, voluntary counseling and testing can play an important role in enabling newly diagnosed people living with HIV to not only talk about their role in prevention, but also to get involved in prevention from the start.

People living with HIV are already making a difference in the region. For example, as a result of APN+'s work, leadership has been strengthened among HIV-positive people serving on the APN+ Steering Committee.

"The chairperson of the Thai Network of People Living with HIV/AIDS was initially very quiet and shy, but has now taken a leadership role in the HIV epidemic. He has met with the Minister of Health and is negotiating issues of access to antiretrovirals. Thanks to people like him, who have been able to network and mobilize civil society, the role of people living with HIV has really had an impact," Greg says.

Greg recognizes that there are still many challenges to face, including the greatest challenge of really addressing the stigma and discrimination surrounding HIV.

"We can't do this without empowering ourselves as people living with HIV to speak out and advocate on behalf of people living with HIV," Greg believes. In the next year, Greg hopes to personally mentor a local Thai person living with HIV to become APN+'s Regional Coordinator. "I know that I am making a difference, although it is sometimes hard to measure how much of a difference. It is really gratifying to see friends and colleagues become strong and dedicated leaders."

Written by Nadia Carvalho, POLICY Project Mekong Regional Manager.

"I know that I am making a difference, although it is sometimes hard to measure how much of a difference. It is really gratifying to see friends and colleagues become strong and dedicated leaders."

■ Greg Gray



VLAD KONDRATUK

NADIYA ZHYLKA

Dr. Nadiya Zhylka works as a head of the obstetric-gynecologic service in Ukraine, but she does not look like a typical government official. When she talks about HIV, she can barely contain her emotions. As an obstetrician-gynecologist, she has been working with HIV-positive women since the beginning of the 1990s.

“I will remember the first HIV-positive pregnant woman I met for all of my life,” Nadiya says. “She was only 17 and knew nothing about HIV. We did our best to help her to deliver a healthy child. But most women had an abortion at that time. Sometimes it was recommended by the doctors who were not informed about ways of [preventing] HIV transmission from mother to child.”

UNAIDS estimated that there were about 360,000 adults living with HIV in Ukraine at the end of 2003, which constitutes about 1.4 percent of the adult population and is the highest HIV prevalence in Eastern Europe and Central Asia. The registration of HIV-positive pregnant women in Ukraine, Nadiya says, began in 1998. At that time, there were only about 500. This figure has grown by about 20 percent annually.

Unfortunately, the general public and some medical staff know little about HIV and this often leads to discrimination against people living with HIV.

“At the beginning of the 1990s, there was terrible stigmatization and discrimination,” Nadiya says. “For example, when an HIV-positive woman was in a maternity hospital, everybody knew about that. Everybody avoided her ward. When she tried to go out of her ward, she was pushed back inside.”

Although non-disclosure of diagnosis is a right guaranteed by Ukrainian legislation it is seldom fulfilled in practice. According to Nadiya, members of the medical staff who violate confidentiality do not understand how this disclosure may threaten their patients.

“Sometimes they put special marks on medical cards of HIV-positive women. This was done allegedly to protect doctors and stop spreading HIV infection, but eventually everyone avoided these persons,” Nadiya explains.

Mandatory pre- and post-test counseling remained a simple formality for a long time. As Nadiya recalls, “There was a case when two men were told simultaneously about test results, and for one of them the result was positive. There was no counseling, they just told him. Imagine how he felt at that moment. Sometimes they just called relatives and told them about test results.”

While working in Kirovohrad in the mid-1990s, Nadiya understood that changing the situation

for people living with HIV required action at the state level. She became deputy head of the Kirovohrad city maternity and childhood protection administration and then was appointed to the Ukrainian Ministry of Health in Kyiv. Nadiya started to study the situation and to look for the cause of negative attitudes and discrimination toward HIV-positive people.

“It turned out that independent Ukraine had virtually no documents that regulate medical activities,” Nadiya explains. “Everybody used orders issued in Soviet times. We started to work on such documents, but we lacked information. We had to literally pick up crumbs of it.”

Building on technical assistance from the POLICY Project, Nadiya says, “We could change the situation and develop new, modern regulations. Our goal was to optimize medical help in the fields of obstetrics, gynecology, and neonatology, including help to persons living with HIV. We succeeded in developing standards for obstetric-gynecological care for the first time in Ukrainian history.”

At the same time, Nadiya understood that regulations themselves would not solve the

problem. She traveled to various parts of the country and taught doctors, nurses, and midwives.

“Although I’m now in an executive position, I do my best not to lose connection with reality,” Nadiya explains. “During my trips to regions, I always visit maternity hospitals, antenatal clinics, and maternity wards in local hospitals. I need to see how doctors work and how they treat persons living with HIV.”

Over the past few years, Nadiya and her colleagues have taught about 12,000 obstetricians-gynecologists. “We teach people not to separate HIV-positive women from others, teach them to be tolerant,” she says.

According to Nadiya, now people treat persons affected by the epidemic with more tolerance and

their attitudes toward HIV has become calmer. The most important thing is that now more healthcare providers know about the ways of preventing HIV transmission from mother to child.

POLICY and its partners supported a study of the barriers HIV-positive pregnant women face

“When I was a simple doctor, I saw that people needed me and I knew how to help them. Now ... I often do not see the people for whom I work. However, I know that it is my task to help women living with HIV, help children to be born without HIV infection, and to fight discrimination of HIV-positive people.”

■ Dr. Nadiya Zhylyka

in accessing reproductive healthcare. Nadiya explains, “During interviews, women told about the attitudes of medical staff members toward them, whether they felt discriminated against, how good was the consulting, and so forth. This helped us to see the practical results of our work and understand the points that required special attention.”

According to Nadiya, the research project “united doctors, specialists from other fields, and representatives of NGOs. In 2004, with POLICY support, the Ministry of Health has developed a Ukrainian national strategy for prevention of HIV transmission from mothers to children for years 2005–2011. Its implementation includes initial prophylaxis of women, family planning for HIV-positive people, prophylaxis for HIV transmission from mother to child, and treatment and support of HIV-positive women and their families. Our goal is to decrease the rate of HIV transmission from mother to child to 3 percent.”

“If we reach [this goal] I will say that I’ve done my job,” says Nadiya. “But it doesn’t mean we can stop—we have to develop methods of consulting of children, pregnant women, and teenagers ... Last year, the voluntary counseling and testing protocol was developed. We need to constantly inform medical staff, but the main thing is to inform people of means of HIV prevention and cultivate their responsibility for their own health. I am willing to talk about it

day and night. Yes, HIV infection exists, but we don’t have to fear and tear away from HIV-positive persons.”

According to Nadiya, HIV spreads faster than medical study programs and practices can change, but now HIV-positive women in Ukraine have the possibility to receive medical care and give birth to healthy babies. The number of abortions because of HIV infection, for example, has decreased significantly. In 2004, about two-thirds of the 3,000 HIV-positive pregnant women continued their pregnancies to term and delivered.

“Sometimes I feel frustrated, because I do not see the results of my work,” Nadiya explains. “When I was a simple doctor, I saw that people needed me and I knew how to help them. Now, it is more complicated, because I often do not see the people for whom I work. However, I know that my task is to help women living with HIV, help children to be born without HIV infection, and to fight discrimination of HIV-positive people.”

“Now I look into the future with optimism,” Nadiya says with a smile, “because we have done the main thing—we have built the system.”

Written by Anton Topchiy, a journalist with Internews-Ukraine based in Kyiv.

*“... I still have a normal life,
it could be a long life even.
I’m still living and being
helpful to my family and to
others. That is my message.”*

■ Pham Thi Hue



JULIAN WAINWRIGHT



NGUYEN DUC B NH

PHAM THI HUE

When Pham Thi Hue first heard she was HIV positive she believed she was dreaming.

“I thought I had not regained my senses when I heard those words,” she says. Hue was lying on the operating table after having a cesarean section for the birth of her son in 2001 when she heard two doctors discussing the results of her blood test.

“One said, ‘This woman has tested positive to HIV.’ I thought I hadn’t regained consciousness, but then a doctor whispered to me, ‘You have just had a baby boy, he is very pretty.’ That’s when I realized I was awake. I felt miserable, but collected my wits by telling myself I would keep it a secret.”

But doctors paid little regard to Hue’s right to keep her status to herself.

“A day after that, doctors informed everyone in my family except me,” she says.

Immediately Hue became an object of fear and was subjected to a cascade of incidences of stigma and discrimination.

“Every nurse and doctor in the hospital was afraid of approaching me. I was quarantined with my baby in a separate room in the hospital. After that, both our families became very scared, they refused to receive us at home, although

they still loved us very much. They rented us a separate apartment, which was located quite far from them.”

A year of torment followed for Hue and her husband.

“I often felt lonely and sad as people avoided and kept away from me. I was also worried for my baby who was discriminated against although he is not carrying the virus,” Hue says.

Then, in 2002, Hue attended a seminar on stigma and discrimination in Hanoi organized by the POLICY Project. It proved a turning point in her life.

“It was the first time I talked about my story. I had never dared share with anyone, including my husband, about my feelings, my difficulties, my worries, and about the heavy stigma and discrimination against people living with HIV like me and what I had suffered because of it,” she says. “I suddenly felt relieved, easy, and happy after speaking out about it.”

The determined 24-year-old says following the seminar she decided not to allow herself and others like her to be marginalized.

“In the beginning, I did not mean to set up a big group with such a large range of activities. At that time, we were four women with HIV

and we just came together to talk and help each other in our daily work.”

But when others began joining the discussions Hue realized they had the basis for a group and Flamboyant Flower was born. Named after the rich red flowers that are the most visible symbol of Haiphong, Hue wanted the group to help people living with HIV become similarly visible. When *Time Magazine* named Hue as one of 20 Asian heroes under 40, it said she was “making herself seen and heard so others will not be invisible.”

“We go to positive people’s houses and talk to their families to help them understand more about HIV and its transmission. We also go to take care of the people living with HIV who develop AIDS and their families. We buy them things like clothes, blankets, mosquito nets, and so on. We also help to hold funerals for people who die of AIDS, since they are often from very poor families,” she says.

The group also tries to spread understanding of HIV in the community. As Hue explains, “We hold talks every month in our area to give local people more information and knowledge about HIV. We also set up a hotline and offer counseling to people living with HIV.”

It is a measure of Hue’s commitment that the 24-hour hotline is also her home phone. Hue’s group distributes condoms and leaflets, visits local businesses to raise awareness of issues related to HIV, and counsels families on the best way to care for relatives who are ill.

“We also provide material and spiritual support to children of people living with HIV. We give books, notebooks, pens, and so on to the kids,

and organize parties for them during the mid-Autumn festival,” Hue says.

The POLICY Project has supported Flamboyant Flower through training on the delivery of counseling services, public speaking, policy advocacy, and project management as well as providing authoritative information on HIV and antiretroviral treatment. Hue says the group plans to continue to extend the range of its activities and in the future plans to work on behavior change with drug users.

Hue says she has seen improvements in the level of stigma and discrimination since she was first diagnosed.

“The stigma and discrimination against people living with HIV is becoming less now, and their lives have been improved a bit. However, it remains a very serious problem.”

Despite or perhaps because of Hue’s high profile, her family still suffers discrimination. Last year, Hue was forced to take her son out of kindergarten because of pressure from other parents and the school. When she approached the kindergarten and offered to give a presentation to the other parents on HIV, she was refused.

The determined Hue has since found a new kindergarten for her son, but the rejection still hurts and fuels her hope to provide more help to the children of people living with HIV in the future. It has not, however, stopped her from addressing discrimination when she sees it.

“Previously, when I realized someone’s discrimination toward me, I often tried to keep away from them. But I have changed now, I will

■ A TRIBUTE FROM A FRIEND

Recalling my first meeting with Hue and her son at a seminar sponsored by POLICY in Hanoi, I took out the photo of many people with Hue, in a blouse and with natural hair standing among them. Hue is like many other women living with HIV, but she is of extraordinary energy and perseverance. She has encountered indifference and stigma face-to-face, and won over the mischievous malady.

Aside from the sacred mission of a wife and mother, she is quite preoccupied with her active participation in HIV prevention. In the extreme suffering and sorrow, Hue has found some joy in her social activity. In early 2002, she was lucky enough to be recommended to the Hai Au Club by a member of the ward

women's union. There, she took part in the programs for cultural performance and propagation. Then she was selected as one of the three club members to attend the seminar on stigma.

Hue said, "I've met with some other people like me coming from the provinces. Talking to a crowd for the first time, I was trembling like a leaf. I knew I wished to tell people about HIV and about what I was experiencing. I wished to do something useful."

In early 2005, I met Hue again at a training workshop on medical treatment for HIV-positive people, also sponsored by POLICY. I was astonished to find her more charming and self-confident than before. After the

dinner, I invited her for coffee. As we had not seen each other for a long time, we could only encourage each other.

According to Hue, HIV-positive people can benefit greatly from skills building opportunities. She says, "Now I feel more self-confident ... I've got more friends and better relations. I feel very happy now. As a result, I've formed a group of self-reliance for my peers in Haiphong. For the time being, I'm a collaborator of quite a few projects and organizations—I'm even a United Nations volunteer and a member of the coordinating committee of the National CCM Fund."

Written by Dong Duc Thanh, POLICY/Vietnam GIPA Officer.

come and talk to them about HIV/AIDS and its transmission."

Hue says she wants to live in a way that is an example to other people living with HIV. She says, "I tell other positive people that I'm also a person with HIV, and I still have a normal life, it could be a long life even. I'm still living and being helpful to my family and to others. That is my message."

Hue says that since being named an "Asian Hero" she has found people more ready to

listen to her and to other people living with HIV, but she feels she is just one hero among many.

"There are so many people in the positive community who are heroes to me. Just living every day makes them heroes."

Written by Bill Bainbridge, a freelance journalist based in Hanoi, Vietnam.



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